394 Conceptual approach of an educational evaluation system for patients

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Introduction: in the perspective of therapeutic education for patients with cystic fibrosis, the CFR centre of Nantes accepted to participate in the validation of aneducational evaluation system for patients. The evaluation system was elaborated by the Laboratory of pedagogic health – Bobigny-University Paris in 2005. The objective was to assess patient's evolution in self-care competences.
Methods: we tested it with 40 patients older than16 years old. We had to give a clear explanation to secure them. Each patient passed the educational evaluation system three times during one hour every three month. The system included: a knowledge questionaire with certainty degrees, self-evaluation about strategies to solve a situation/problem, adaptation and anticipation for a new situation, self esteem, effectiveness about treatments, life plan, control of the gesture or the technique, effectiveness of one gesture or the technique. After every activity the patient and the care provider discussed together about quotation and reported it on a star evolution tool. Finally, the patient could express himself about his personal star tool. If needed if the patient agreed, a therapeutic education activity could be planed.
Results and Conclusion: This approach prompted patients to be more aware of their health condition "it helped me to learn more about my disease" "it will be interesting to do it once a year" " I am surprise of my good knowledge". The medical team said, " This evaluation system helped us to improve our educational approach". We can suppose that this co-responsibility decrease patient's guilty feeling. It is a tool to improve communication between patients and care givers and to push for negotiations.

395* European survey on schooling of children, teenagers and young adults with cystic fibrosis

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Introduction: At the European CF meeting in Prague, the members of the round table on "CF at school" have decided to implement a questionnaire to have an overview of specific measures for patients with cystic fibrosis attending school or university all throughout Europe. We made a questionnaire which was sent to patient's association all throughout Europe. We want to report the answers to this questionnaire during the meeting in Brest.
Materials and Results: The questionnaire was divided in following parts:
- Report of specific measures for patients with CF attending school/university: emergency protocols, possibility of medical care during school hours, specific rest rooms, segregation policy, hygiene protocols, hydration protocols, administration of pancreatic enzymes, Double set of books, possibility of making up missed classes, additional time to catch up on the homework, adaptation of school time, accommodations for class trips, work that might create risks, special room for storing oxygen and medications.
- Availability of a document describing general precautions and/or specific treatment for children at school with CF.
- Specific guidelines during sports: possibility of drinking, inhaling bronchodilators and resting during and after sports, adaptation of sports to the breathing capacities of the child, specific hygiene recommendations for swimming pool, special accommodations for sports test
- Other specific information such as assistance services for children with respiratory failure, possibility of intervention at the school to explain the disease.

Conclusion: The answers to this questionnaire are now collected and will be reported in Brest.

396* Pedagogic drivers in therapeutic education for patients with cystic fibrosis

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Introduction: Patient education requires that caregivers integrate pedagogical concepts to facilitate ownership by the patient of self-care and adaptive skills. For caregivers, the pedagogical driver is designed in such a way that it gives them support to strengthen their competence in teaching.
Methods: Several pedagogical drivers have been created by the GÉTHEM, then collected in a binder and made available to medical teams of all CF centres. Each pedagogical driver includes three parts: care giver's activity, patient's activity, learning approach and evaluation criteria. Example taken is "State mode of action of nebulised drugs and choose nebulization time to airway clearance clearance treatment". It is used with a tool called "Breathing plan": a week is represented, the patient places stickers on each day for his activities: job or school, sports, leisures. He then places down his different respiratory treatments and airway clearance treatment session. Finally, the patient explains the target of each medicine and the best moment to do it. The patient evaluates himself how he manages his different treatments. A real discussion is established between the patient and the care provider about what he does, what would be better and what is possible to do. For patients whose experience of illness has at some point induced a threat to their senses of security and identity, it is a process of personal transformation.
Conclusion: this approach leaves the patient decide himself a strategy to change. Most of the patients are satisfied. It allows the team to apprehend patient's difficulties or needs. The medical team understands better the process of patient empowerment.

397 Experience of a 1 year therapeutic education program

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Introduction: We report our experience of a therapeutic education program with 8 of our patients.
Material: Necker Pediatric CF Center, in association with "Etoiles des Neiges" Organization set up a 1 year therapeutic education program aiming to explain CF to children between 10 to 13 years and how to use this knowledge in their daily life. The other purpose was to teach them how to behave as a champion.
The program was divided in 2 parts: 4 educational sessions on the disease and its treatments, at the hospital; alternated with 4 week-ends practicing sports with champion advises, and using what was taught to them.
The educational program includes 8 items: normal lung function, CF pulmonary disease, Physiotherapy, Normal digestion, CF related pancreatic dysfunction and nutrition, Hygiene, daily treatment. New education tools have been implemented for each session.
The risk of cross-infection was minimized by a strict policy: all children had the same sputum colonization which was checked before each meeting. Masks were worn during indoors sessions.
Results: The autonomy of the children for self treatment was increased. After the sessions, children better coped with their CF at school or with there friends. They understood better their body functioning and how to prevent infection.
Conclusion: The educational program improved children's understanding of their disease and supported their autonomy, but as they are teenagers, it needs to be continued. We project to see the group at least once a year. For the first time, most of our patients had the chance to meet and spend time with other CF patients, they were able to share their experiences and realized they were not alone.